

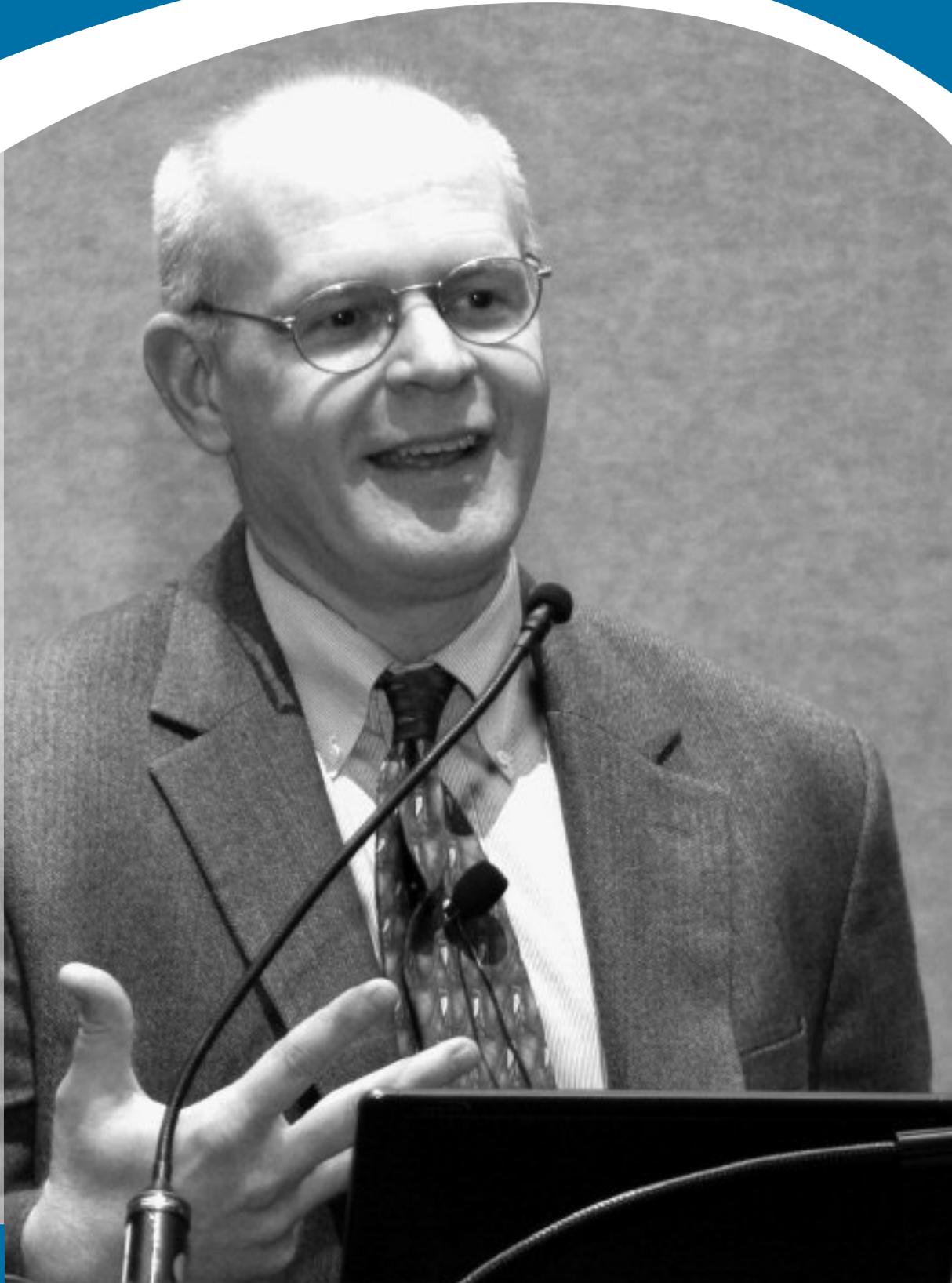
SPONDYLITIS PLUS

spring 2007

MICHAEL WARD, MD
AT ACR

CELEBRATING
THE KAUTZ FAMILY'S
LONGSTANDING
SUPPORT

HOW YOU CAN
HELP ADVANCE
GENETIC RESEARCH



SPONDYLITIS ASSOCIATION OF AMERICA

P.O. Box 5872
Sherman Oaks, CA 91413
Phone (818) 981-1616
Fax (818) 981-9826
e-mail: info@spondylitis.org
www.spondylitis.org

SAA MISSION

To be a leader in the quest to cure ankylosing spondylitis and related diseases, and to empower those affected to live life to the fullest.

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UPFRONT



MY FIRST SIX MONTHS AT SAA HAVE BEEN VERY BUSY. SAA's calendar of scientific meetings, Patient Education Symposiums and support group meetings has provided several opportunities for me to observe and participate in the various programs.

In November, the SAA staff and I traveled to Washington DC to participate in the annual scientific meeting of the American College of Rheumatology. This year's meeting brought together more than 10,000 clinicians and researchers from around the globe to share information and foster advances in rheumatology.

While in the DC area, we presented a Patient Education Symposium that brought together more than 100 SAA members who spent the day interacting with some of the leading specialists in the field of spondylitis. That same week, we held our annual Medical & Scientific Advisory Board Meeting. It was very inspiring to meet and interact with the many talented physicians and researchers dedicated to finding the cure and advancing the treatment of AS and related diseases.

Later in November, I had the opportunity to visit San Diego and attend a Support Group Meeting led by Mike Supancich, one of SAA's National Board members. I was impressed by the amount of helpful information and tips shared among the members of the group.

As I indicated in my first column, in addition to SAA's focus on key research projects, we plan an aggressive calendar of Patient Education Symposiums throughout the year. Arrangements have been finalized for a presentation in Chicago on March 10th, and we're now confirming plans for a symposium in Los Angeles in May. The Los Angeles meeting will coincide with SAA's first training session for group leaders from among our network of support groups across the country. In addition, later this summer, we will be releasing additional Fall and Winter dates for meetings in other key metropolitan areas.

I hope you find this issue of Spondylitis Plus informative and useful.

Katherine Culpepper
EXECUTIVE DIRECTOR



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GENETIC RESEARCH

Dear SAA,
I really enjoyed reading Dr. Maksymowych's article regarding bisphosphonates. It is very interesting. Several months ago, I received a newsletter for men who have prostate cancer, in which it recently warned of a rare side effect of using IV bisphosphonates. Could Dr. Maksymowych please shed some light on this issue?

JAKE SIMMONS
Lake Placid, NY

Dr. Maksymowych responds: (reprinted from 2006) the issue raised by this reader describes a report of 63 patients with bone malignancy that developed aseptic necrosis of the jaw – essentially death of the bone. It should be borne in mind that additional factors such as chemotherapy, recent dental surgery, steroids, and oral infections could have been a factor and were present in most of these patients. No similar cases have been identified in other large scale and long-term studies of bisphosphonates. Furthermore, this complication was not observed in pre-clinical studies where higher doses were used than currently used for osteoporosis. There is now safety data on an estimated 20 million patient-years for one bisphosphonate, alendronate. It is important to continue to observe and carefully evaluate and distinguish chance associations and causal relationships.

Dear SAA,
I am pleased to send you this donation, though I know that it is small, I hope that it will help in some way. I raised this money

by playing my violin and by singing in the town square of Chautauqua, New York this summer. Because my dad has spondylitis, I wanted to help find a cure, and since my Bat Mitzvah is coming up, I decided to do this for one of my mini community projects. I really worked very hard to earn this money and I hope that it will help.

JAINIE WINTER
(address withheld)

Editor's note: we received this wonderful note by mail along with an accompanying donation check in the amount of \$54.25 Thank you, Jainie.

Dear SAA,
I really appreciate the information I receive through your magazine and web site. I'm a 62 year old male who has had ankylosing spondylitis more than half my life (the onset was in about 1972). I've suffered much pain over all those years, and during the past 5-6 years have become increasingly bent forward. I learn to cope as it progresses and don't let it stop me, but it does get frustrating at times (particularly now as I can't do many simple things I always did in the past – like look up to put something on a shelf or do some maintenance project around my house).

Having just moved halfway across the US (from Washington, DC to Kansas City, MO), I now have to find a new doctor to assist me. I'm using your online list/recommendations in attempting to select one. Please keep helping us with all relevant information. It

may not straighten my spine, but sometimes it helps to know I'm not alone, and to find out the latest information.

I believe it's important for everyone to keep a positive attitude. I hope others who suffer from ankylosing spondylitis or any other serious ailment also can learn to accept that, no matter how bad it may seem, there are others who suffer from even much worse ailments. Over the years I've watched close family and personal friends die from those worse ailments. Mine's not nearly that bad.

To all of the SAA staff and volunteers, thanks for being there. And thanks for providing a source of information about what's going on. It's very important. Folks like me can use whatever support and information you can give us.

Take care,

KENT HOWERTON
Kansas City, MO

LETTERS TO THE EDITOR

Dear Readers: We want to hear from you, whether it be informative, uplifting, or a gripe you need to express. Include your full name, address and daytime phone number.

We reserve the right to edit for space and clarity.

Please send letters to:
Laurie.Savage@spondylitis.org
Letters to Editor/SAA
P.O. Box 5872, Sherman Oaks, CA 91413

CALL TO ACTION: GENETIC RESEARCH NEEDS YOU!

Update on TASC (“Triple A” Spondylitis Consortium)

In recent years, a great deal of progress has been made in shedding light on the potential causes of AS and in seeing the advent of improved treatments that show tremendous hope for people with AS and related diseases. Much of this is due to the work of dedicated researchers, but also to people like you who have participated in the NASC study, (The North American Spondylitis Consortium), which evolved from the AS Family Genetic Project. Data generated in that project include the discovery of regions on chromosomes that further our understanding of susceptibility toward AS. In addition, the data suggest that genes may play a significant role in severity and outcomes of the disease. New and more established theories are being explored in regard to the potential relationship between microbes, genes--particularly B27--and inflammatory mechanisms in the gut/blood barrier that might be involved in triggering AS and enteropathic arthritis.



Photo: Chris Miller

Introducing Omolade Ogun, the SAA's study Coordinator for TASC

Omolade Ogun was born and raised in Lagos, Nigeria. She attended the College of Medicine, University of Lagos, where she completed a six-year combined Bachelors of Medicine/Bachelors of Surgery degree. Subsequently, she trained as an intern at the Lagos University Teaching Hospital in 2001. In 2002, she moved to Los Angeles. She has volunteered at various healthcare facilities in Southern California. She works part time as a Health Screener, performing screening activities at health fairs, where she has been able to use her medical knowledge to educate people on health issues. Her passion is to educate patients and treat them with the respect and individuality that allows them to make some of the most important decisions in their lives.

Omolade worked at the David Geffen School of Medicine at UCLA in Westwood, California, as Clinical Research Associate in a major multi-center, double blind, placebo controlled study to assess Lung Function

Decline in Chronic Obstructive Pulmonary Disease patients taking the trial medication. She credits her mentor, Donald Tashkin, MD, and the time she spent at the David Geffen School of Medicine for inspiring her to dedicate her time to clinical research. She also strongly believes that energetic and creative dedication to clinical research leads to outstanding biomedical achievement that translates to significant changes in clinical settings. This is what led her to join the Spondylitis Association of America as Study Research Coordinator in October 2006.

The Interrelated Projects of the Grant

1. To identify the genes that cause AS
(Matthew Brown MD, John D. Reveille MD)
2. To identify the genes that predict severity and outcomes
(Michael Weisman MD)
3. To identify the spectrum of related diseases in family members of people with AS
(John C. Davis MD MPH)
4. To determine how the genes interact with each other
(Momiao Zhong PhD, Xiudong Zhou MD)

WE NEED YOUR HELP!

A Call for Research Participants

- ▶ People who have been diagnosed with AS
- ▶ Non affected spouses of people with AS
- ▶ Non affected friends of people with AS

If this describes you, and you would like to help, and have not already participated in an AS Genetic Study, please call: Omolade Ogun (800) 777-8189 x224 or email info@asresearch.org

The SAA is grateful to close to 100 people with a confirmed diagnosis of AS who have contacted us since November to find out how to enroll in the study.

CIGARETTE SMOKING AND ANKYLOSING SPONDYLITIS

By Professor Matthew Brown, Princess Alexandra Hospital, Brisbane

Many people, most of them smokers, will not read this article further than this because they think they've heard it all before. Patience please! If you have AS and smoke, you really need to think hard about giving up, even more than people without AS. The reason is because there are many factors peculiar to AS that smoking detrimentally affects.

Why write this article now? Because we have just analyzed the data from the first 6 months of our AS Specialist Clinic in Brisbane, and the standout finding was that AS patients who smoke had far worse disease activity than those that do not, with a mean Bath Ankylosing Spondylitis Disease Activity Index which was 50% worse than non-smokers. That's a huge difference.

What are the effects of smoking in AS?

- Smokers are more likely to develop AS.
- AS is associated with a 50% increase in mortality rate compared with age- and gender- matched people without AS, mostly due to cardiovascular disease. Smoking will exacerbate this.
- AS is commonly associated with lung disease. In a recent study 40% of AS patients were found to have significant lung abnormalities on close examination. Also, because AS leads to restriction of chest wall movement due to fusion of the thoracic spine and rib joints. AS patients have less respiratory "reserve" than those without AS. So if you smoke and do even more harm to your lungs, then you will develop respiratory failure much faster than people without AS.
- AS commonly causes osteoporosis. People who smoke are twice as likely to develop hip fractures than those who don't, so why add another risk on top of the risk you have with your AS anyway?
- Smoking is associated with stomach



ulcers. AS patients are at increased risk anyway of stomach ulceration through NSAID usage. So smoking just adds another risk.

- If you get smoking-induced chronic bronchitis, you may be excluded from receiving TNF-blocker treatments, which are extremely effective in AS.

There are lots of other reasons why you shouldn't smoke which apply generally and are not specific to AS, such as:

- It causes a wide range of cancers
- It causes heart attacks, strokes and peripheral vascular disease (leading sometimes to the need for amputations)
- It costs a lot of money
- It makes you smell bad

So what can you do to stop smoking? Here are some tips to help you quit successfully.

- Set a date to quit. Choose a date when there will be a low amount of pressure on you, two to three weeks from now.
- Plan for the most risky times. Plan activities that will not expose you to situations where you will be tempted to smoke.
- Enlist the support of your friends and family.

- Hold a clean up ritual. Clean cigarettes out of your car, handbag, briefcase and house. Get rid of ashtrays and lighters.
- Think of yourself as a non-smoker from the moment you quit.
- Understand withdrawal symptoms. These are reactions that your body may experience as it flushes itself of nicotine and other chemicals. Think of these as recovery symptoms. Some recovery symptoms will come and go over a period of a few days, and most are gone within two to three weeks. Emotional symptoms, such as anxiety and irritability, are closely tied to the physical reaction of your body as the nicotine leaves your system.
- Remember the 4 'D's.'
 - ▶ Delay acting on the urge to smoke. After five minutes, the urge to smoke weakens and your resolve to quit will come back.
 - ▶ Deep breathe. Take a long slow breath in and slowly out again. Repeat three times.
 - ▶ Drink water.
 - ▶ Do something else. Take your mind off smoking by taking action.
- Reward yourself. Put aside the money you would have spent on cigarettes in a jar – you may be surprised by the amount of money you can save.
- Remember, having "just one" will hurt. This is the way that most people go back to smoking.
- If you have a relapse, don't despair and don't give up on your plans to quit. Most people who have successfully quit smoking for good have made several serious attempts. Every day that you have spent smoke-free makes your body healthier and helps to break your habit and weaken your addiction.

Do something to help yourself. Stop smoking!

Reporting from the American College of Rheumatology Scientific Meetings, 2006

The 71st Annual Meeting of the American College of Rheumatology (ACR), the professional association of rheumatologists in the United States, was held in our nation's beautiful capital city of Washington, D.C. from November 8th through November 11th, 2006. The combined attendance of the ACR and Allied Rheumatology Health Professional (ARHP) members was over 13,000, making it a record-breaking year for participation in this important scientific meeting devoted to the rheumatic diseases.

The annual ACR scientific meeting provides an opportunity for pre-publication examination and review of work conducted by researchers over the course of the previous year. Over 100 studies presented at this year's ACR were related to ankylosing spondylitis and other forms of spondyloarthritis. The abstracts from the meeting provide us a unique opportunity to report on the considerable work that is being done, both in the U.S. and worldwide, to develop better treatment options and, ultimately, to find the cure.

On the Saturday prior to the opening of the scientific meeting, SAA sponsored a Patient Educational Symposium that brought together 160 patients, family members, friends and SAA supporters with some of the leading experts in the field of spondylitis. Drs. John Reveille and Michael Ward and Physical Therapist, Ms. Victoria Gall presented lectures on advances in research, workplace and disability issues, and disease management. In the convention center's exhibition area, SAA's booth welcomed hundreds of physicians and researchers who eagerly signed up to receive information about our programs and services, as well as brochures and educational materials to assist them with their spondylitis patients

Serum Matrix Metalloproteinase 3 is an Independent Predictor of Structural Damage Progression in Patients with Ankylosing Spondylitis (AS)

Authors: Walter P. Maksymowych and colleagues from Europe and Canada

Objective: Researchers in this study sought to identify blood serum biomarkers as predictors of patients at risk for structural damage progression in AS.

Results: Serum matrix metalloproteinase-3 (MMP-3) – an enzyme, was found to be elevated in two-thirds of patients who went on to further radiographic damage in AS.

Conclusion: Dr. Maksymowych and his colleagues strongly suggest that the results of the study demonstrate that testing for this enzyme could be a useful and inexpensive screening tool for patients with AS to determine their likelihood of going on to more severe disease.

Methotrexate 20 mg (injected under the skin) in AS – No Efficacy Over 4 Months Treatment in an Open Label Pilot Study

Authors: Hildrun Haibel and colleagues, Germany

Objective: There has been an ongoing debate among some clinicians for many years with regard to the use of Methotrexate (MTX) in AS patients. The goal of this study was to examine the potential therapeutic effect of MTX 20 mg given weekly by injection under the skin in active AS.

Method: 20 patients were enrolled in the study for a total of 16 weeks. All of the patients were experiencing active disease associated with spinal pain and 7 of whom also had peripheral joint involvement.

Results: The researchers reported that 35% of the patients had some response to the treatment, but none achieved partial remission of the disease using the ASAS scoring system. Seven patients experienced a non-significant decrease in the number of swollen joints.

Conclusion: The researchers of this study concluded that MTX did not demonstrate a benefit for the axial (spinal) symptoms in patients with active AS beyond an expected placebo-response. Thus, in spite of current practice, they recommended that MTX not be used for this indication.

A PRIMER ON HLA-B27 IN ANKYLOSING SPONDYLITIS A group of genes on chromosome 6 codes for the HLA (human leukocyte antigens) antigens play a major role in susceptibility and resistance to disease. Specific HLA antigens influence the development of many common disorders. Some of these disorders, which include ankylosing spondylitis (AS), are autoimmune related and inherited in a multifactorial manner. When a person has the specific HLA antigen type associated with the disease, he/she is thought to have an increased chance to develop the disorder. The HLA antigen associated with AS is called B27. People with the HLA-B27 antigen are thought to have an increased chance (or "genetic susceptibility") to develop AS; however, it is important to understand that a person without this antigen may also develop AS. This means HLA antigen testing is not diagnostic or accurate for prediction of the condition.

Serum Retinol (vitamin A) levels are Decreased in Ankylosing Spondylitis and are Independent of Disease Activity

Authors: Finbar D. O'Shea, Robert D. Inman and colleagues, Toronto, Canada

Purpose: Vitamin A (retinol) plays an important role in bone structure and function, and treatment with retinoids has been associated with bone abnormalities that mimic certain diseases that include spondyloarthritis. In addition, in mice, the lack of the gene CYP26A1 has shown to cause symptoms that mimic those of retinol over-dosing.

The specific aims of this study were: 1. to compare serum (blood) levels of retinol between AS patients and unaffected controls; 2. to correlate retinol levels with disease activity in AS; 3. to identify any genetic association with the CYP26A1 gene.

Methods: The researchers tested for the genetic marker, and measured serum levels of retinol in both AS patients and controls. They also administered tests to the AS group in order to assess disease activity.

Conclusion: The results of this study suggested that contrary to expectations, the serum level of retinol in the AS patient was lower, as a group, than that of the unaffected control group. The researchers also uncovered the fact that retinol did not impact disease activity. Furthermore, although genome-wide scans have implicated p450 genes, such as CYP26A1, in the genetic susceptibility to AS, the researchers caution that, to date, no biological basis for such an association has been resolved. This study was not able to yield a distinct genetic association of CYP26A1 with AS, although researchers believe that further analysis of the genetic determinants of retinol metabolism in AS are warranted.

Low Influenza Vaccination Rate among Adults Receiving Immunosuppressive Therapy for Systemic Inflammatory Diseases

The Study: It is recognized by rheumatology professionals that annual influenza shots are recommended for individuals (adults) who have immuno-deficiencies, which include those that are drug-induced, such as TNF Inhibitor therapies. The aim of the study was to evaluate whether and to what extent SID patients sought vaccination.

Conclusion: The study results suggested that there is a low vaccination rate in SID patients. Two primary reasons were associated with non-compliance: 1. failure to bring it up (by the health care professional) 2. patient's fear of side-effects.

The study concluded the importance of improving patient and physician awareness with respect to the vaccination of patients at high risk of influenza complications.

Screening and Prevention of Mycobacterial Infections in Patients taking TNF Inhibitors; the Value of Annual Tuberculin Skin Testing

Purpose: TNF inhibitor therapy exposes a person to a higher risk of contracting a mycobacterial infection. Hence, the reason that Tuberculin Skin Tests (TST) are recommended prior to starting TNF Inhibitor therapy to screen for latent tuberculosis infection (LTBI). The researchers who conducted this study reviewed the results of yearly TST testing at one institution to evaluate whether annual testing of patients on TNF Inhibitor therapy can be recommended.

Conclusion: Retesting of 379 patients receiving TNF Inhibitor therapy revealed LTBI in 3.5%. One patient who previously had tested negative for a mycobacterial infection (MAI) developed symptoms and cultures led to a new diagnosis of MAI. Hence, the researchers who conducted the analysis of the data for the study, suggested that annual TST is warranted in order to catch previous false negatives as well as new infections in patients who are receiving TNF Inhibitor therapy.

Juvenile-Onset Ankylosing Spondylitis versus Adult-Onset Ankylosing Spondylitis for the PSOAS Cohort

Authors: Lianne Gensler, Michael Ward, John D. Reveille, Thomas Learch, Michael H. Weisman, John C. Davis, Houston, Tx; San Francisco, CA; Los Angeles, CA; Bethesda, MD. (Editor's note: Dr. Ward is featured on the cover of this issue of *Spondylitis Plus*. He presented at a concurrent SAA patient educational symposium, highlights of which will be featured in the summer issue of this magazine.)

Purpose: Previous studies have suggested that patients with childhood onset of AS have in general more severe disease and poorer outcomes than people with adult onset. In this study researchers evaluated the clinical and radiographic differences between the two groups. Patients in the study had approximately 20 years of disease duration.

Methods: 402 patients with a confirmed diagnosis of AS were enrolled in the study.

Conclusion: The researchers found that in general when patients with childhood onset of AS are compared to those with later onset in adulthood, those with childhood onset demonstrated less spinal disease, more hip involvement that required a hip replacement, and that the juvenile onset group was comprised of more women.

Editor's Note: Each of these studies was published in abstract format and presented at the ACR Scientific Meetings. These data and conclusions should be considered to be preliminary as they have not yet been reviewed and published in a peer-reviewed publication such as the ACR official journal, which is entitled *Arthritis & Rheumatism*.

Tribute Dinner Honoring Jane Bruckel



Once in a lifetime, an organization has the opportunity to honor its Co-founder and retiring Executive Director, the person whose dreams gave the organization life, purpose and vitality. The Spondylitis Association of America had that opportunity this year – to honor Jane Bruckel and celebrate her 23 years of dedication to improving the lives of spondylitis patients everywhere.

This last September, SAA hosted the Jane Bruckel Tribute Dinner at the Jonathan Beach Club in Santa Monica, California. This gala event brought the spondylitis community together to pay tribute to the woman who changed the face of spondylitis in this country.

When diagnosed as a young nurse there was not a single patient resource available for patients to learn about the disease. Jane Bruckel was determined to change that. Today, SAA publishes thousands of educational materials for patients and physicians alike, holds local and national symposiums and provides seed money for the most challenging area of all – spondylitis research – which has brought about multi-million dollar funding from the prestigious National Institutes of Health.

Masters of Ceremonies and SAA Board Members David Hallegua and Brian MacKenzie presided over an evening of tributes, testimonials and reminiscences in honor of Jane's body of achievements. Guest speakers and presenters included Drs. John Reveille, Asim Khan and David Yu of SAA's Medical and Scientific Advisory Board; Former Board Presidents Steve Saltzman and Tom West; and Board Members Ann Howat and Bob Ulrich.

L.A. City Council Member Jack Weiss was on hand to present Jane with a Certificate of Appreciation from the city of Los Angeles in recognition of her lifetime of dedication to the spondylitis community. The evening also featured a musical performance by Gravity and a song written especially for Jane by international singer and songwriter, Harold Payne.

Thanks to the commitment of one woman, supported by thousands of SAA members and friends, many spondylitis patients now live more active, more rewarding lives. The Jane Bruckel Tribute Dinner provided a small opportunity for the spondylitis community to show her our appreciation.



Top: Los Angeles City Councilmember Jack Weiss presents Jane with a Certificate of Appreciation from the City of Los Angeles.

Center: Jane and Harry Bruckel with loyal SAA supporters, Jean, Floyd and Damon Kvamme.

Bottom: International singer/songwriter Harold Payne performing a tribute song he wrote especially for Jane.

Kautz Family Foundation

We recently received a generous gift to the Jane Bruckel Research Fund from the Kautz Family Foundation. The Kautz Family Foundation has been a long-time contributor to the Spondylitis Association of America (SAA). Through the years, the Kautz Family has provided significant funding in the areas of advocacy, research and organizational expansion. In 1998, the Kautz Family's support was instrumental in helping SAA gain funding from the National Institutes of Health (NIH) to co-sponsor a major two-day scientific symposium – the first symposium on AS at the NIH. The symposium brought scientists and researchers from related fields for a cross fertilization of knowledge and ideas with AS researchers. It was an important catalyst for SAA receiving funding from the NIH for the Family Genetic Study and providing SAA with the opportunity to recruit key researchers to join the North American Spondylitis Consortium and participate in the Study.

In 2004, Leslie Kautz, daughter of Carol and James Kautz, joined SAA's Board of Directors because she "wanted to join in its passion and creativity for making life better for people with AS." Leslie has seen first-hand the effect that AS can have on a person's life. In the 1970s, she remembers the confusion and uncertainty her family experienced when her brother Daniel suffered the pain of AS without knowing what it was. If the Spondylitis Association had existed then, Leslie believes that the anguish of not knowing and the delay in her brother's diagnosis could have been avoided. She also remembers how information from the SAA newsletter got her brother started on his path to controlling the disease.

Today, the entire Kautz family is committed to the Spondylitis Association and we extend our heartfelt gratitude to them for their generous support and dedication to helping SAA advance research while remaining the largest single source for people affected by AS and related diseases.

Thank you!

Through the years, the Kautz Family has provided significant funding in the areas of advocacy, research and organizational expansion.



The extended Kautz Family gathers in Los Angeles.



Social Security Cost of Living Adjustment (COLA) Update

By Attorney Richard I. Feingold

New Ruling Means Changes in the Assessment of Disability Claims

The Cost of Living Adjustment (COLA) for 2007, released by the Social Security Administration (SSA), will be 3.3 percent. This means that for the more than 53 million Americans who receive monthly benefits from the SSA, **those benefits will increase 3.3 percent in 2007.**

By the Numbers

In 2007, the 3.3 percent COLA increase means that:

- Supplemental Security Income (SSI) benefits will increase to \$623/month for individuals, while the average Social Security Disability Insurance (SSDI) benefit amount for a disabled worker, spouse and one or more children will be \$1,646/ month. Remember, SSI benefits are for a disabled individual only, whereas SSDI benefits may also apply to the spouse and children of a disabled worker.
- **The Substantial Gainful Activity (SGA) amount will increase from \$860 to \$900 gross earnings per month.** Earning over this amount may prevent one from filing for disability benefits or result in a loss of some or all benefits.
- **The Trial Work Period (TWP) amount will increase from \$620 to \$640 gross earnings per month.** During a TWP, a person receiving SSDI benefits is able to return to work, to test their ability to do work, on a trial basis for nine months.

Introduction

By far, the most important evidence that SSA examines in a disability claim is the medical evidence. This is somewhat obvious, because the definition of disability requires that there exist a “medically determinable impairment.”

Medical evidence not only includes objective medical evidence, such as medical signs and laboratory findings, but also other evidence from medical sources, such as the medical history, opinions, and statements about treatment received. Statements that a disabled individual makes about his or her impairments are also considered, but they must be corroborated by the medical evidence in order for them to be found credible and be given weight.

Editor’s Note:

In the November/December 2005 issue of **Spondylitis Plus**, we published the Social Security Administration’s 2006 Cost of Living Adjustment figures. Here are some updated numbers for 2007

To help interpret the medical evidence, and to give binding guidance on disability and other benefit programs, SSA publishes several Rulings each year. In 2006, SSA published a Ruling entitled, “Considering Opinions and Other Evidence From Sources Who Are Not ‘Acceptable Medical Sources’ in Disability Claims; Considering Decisions on Disability by Other Governmental and Non-governmental Agencies.”

In part, this Ruling clarifies how SSA considers opinions from sources who are not considered “acceptable medical sources.” The Ruling recognizes that with the growth of managed health care and the emphasis on containing medical costs, many people get much of their care from health care practitioners who are not doctors. These sources include nurse practitioners, physician assistants and licensed clinical social workers. This Ruling gives guidance on how much weight SSA will give to their opinions.

Q & A

Question: Who does SSA consider to be an “acceptable medical source”?

New Social Security Ruling Means More Emphasis Will be Placed on Medical Providers Who are Not “Acceptable Medical Sources”

Answer: In general, “acceptable medical sources” include, for example, licensed physicians (medical or osteopathic doctors); licensed or certified psychologists (including school psychologists); and licensed optometrists, although SSA may need a report from a physician to determine other aspects of eye diseases.

Question: What categories of non-acceptable medical sources are there?

Answer: There are three categories of sources besides “acceptable medical sources” considered under the new Ruling:

1. “Medical sources who are not acceptable medical sources” (for example, nurse practitioners, physicians’ assistants, therapists, psychiatric social workers and chiropractors);
2. “Non-medical sources” such as teachers, counselors and social welfare agency staff acting in their professional capacity. These sources often have close contact with the individual and personal knowledge and expertise to make judgments about the impairment, activities, and level of functioning over a period of time.
3. “Non-medical sources” such as spouses, other relatives, friends, employers, and neighbors.

Question: Why does SSA draw a distinction between “acceptable medical sources” and other health care providers who are not “acceptable medical sources”?

Answer: One reason is that only “acceptable medical sources” can give “medical opinions,” a judgment about the nature and severity of the impairments and the mental and physical restrictions they cause. In addition, if a patient has had an ongoing treating relationship with a medical doctor, for example, that doctor’s medical opinion can be given “controlling weight,” which can result in a favorable disability determination by SSA.

Question: What factors does SSA consider in deciding how much weight to give the opinions of medical sources who are not “acceptable medical sources”?

Answer: The same factors that are used to evaluate the medical opinions of “acceptable medical sources” can be applied to consider other opinions.

As stated in the Ruling, “These factors include:

- How long the source has known the individual and how frequently the source has seen the individual;
- How consistent the opinion is with other evidence;

- The degree to which the source presents relevant evidence to support an opinion;
- How well the source explains the opinion;
- Whether the source has a specialty or area of expertise related to the individual's impairment(s), and
- Any other factors that tend to support or refute the opinion.”

Question: Is there ever a situation where the opinion of a nurse practitioner or licensed clinical social worker could outweigh the opinion of a medical doctor?

Answer: It is important to keep in mind that although information from these “other sources” cannot establish the existence of a medical disease or illness, the information may be based on special knowledge and provide insight into the impairment’s severity and how it affects an individual's ability to function.

Under the new Ruling, it is possible for the opinion from a medical source who is not an “acceptable medical source” to outweigh the opinion of an “acceptable medical source,” if, for example, he or she has had greater contact with the patient and can provide better supporting evidence and an explanation of the opinion. This can be a great boon to patients who have limited contact with a medical doctor.

Editor’s Note *We are grateful to Mr. Feingold for his ongoing support via the SAA website www.spondylitis.org, where he graciously answers visitor questions on a dedicated message board. Since 1986, he has been representing disabled persons in their Social Security disability claims throughout the United States. He is a sustaining member of the National Organization of Social Security Claimants’ Representatives (NOSSCR) as well as a past Chair of the Chicago Bar Association's Social Security Law Committee. He can be contacted by email at: Rich@FeingoldLawOffices.com and through his website at www.FeingoldLawOffices.com, or by phone at 773.989.9899.*

Disclaimer The information contained in this article is provided as a public service, is general in nature, and does not constitute the rendering of legal advice or legal services. One should consult an attorney before making any decision involving a legal matter, such as a Social Security disability claim.

Driving Safely With AS

Collective fear of a car accident



Ask someone with AS what their biggest fear is and many will answer, “Getting into an automobile accident.”

While there’s always been an emphasis on driving-safety features – good brakes, tires, seat belts, and air bags – when you start to factor in ankylosing spondylitis, all is not equal. There is a lot at stake with fragile ankylosed spines and necks and that raises many questions. Should seatbelts be worn? How should headrests be best used? Airbags?

The best car safety device is a rear-view mirror with a cop in it.

~Dudley Moore

Dr. Nortin Hadler, a member of the SAA Medical Advisory Board, Professor of Medicine and Microbiology/Immunology at the University of North Carolina and attending rheumatologist at UNC Hospitals, graciously offered Spondylitis Plus the input of Dr. Barry Myers, an expert on whiplash

and the biomechanics of the spine, on the use of seatbelts, headrests and airbags by drivers with AS.

THE ANKYLOSED SPINE IS INJURY PRONE

“These are not simple questions,” Dr. Myers thoughtfully said in e-mail. “The severely ankylosed spine is injury prone on very modest exposure.”

Dr. Myers, Senior Associate Dean for industrial partnerships and research commercialization at Duke University’s Pratt School of Engineering, has extensively reviewed injury statistics and medical literature. He has concluded that aside from driving defensively and purchasing the biggest, safest car possible, AS patients would be best served by not doing anything too out of the ordinary in their driving habits. “These will do more to decrease injury rates than other interventions,” he observed.

SEATBELTS AND THE “AIRBAG DILEMMA”

Dr. Myers said he “strongly recommended” the use of seatbelts despite concerns that an AS spine might not be able to withstand the sheering

force the belts might create in a crash. He warned that relying on an airbag to prevent injury, however, was way too risky. “Airbags have a very limited range of accidents that they are effective in, and head impact with an ankylosed spine is devastating,” he cautioned. “Keeping the vulnerable kyphosed spine out of the deploying bag is especially important.”

Dr. Myers also recommended that the headrest be set in a position that minimizes the gap between the head and the rest, and also allows an adequate field of vision for the driver.

“I would not advocate retrofitting the design,” Dr. Myers said.

Finally, there are natural concerns among AS patients that if they were to get into an accident serious enough to cause injuries, they could be at risk by emergency rescuers who do not understand the fragile nature of their backs and necks.

The SAA has done a yeoman’s job in advocating better training for emergency medical technicians, although Dr. Myers noted that spinal precautions were nonetheless pretty much standard procedure at accident scenes.

ALL DRIVERS SHOULD WEAR SEATBELTS

Dr. Hadler also kindly provided Spondylitis Plus with the expertise of another friend and colleague, Dr. Gunnar Andersson, MD, PhD., an internationally recognized expert in musculoskeletal disease and injury who is also credited with designing the unique seats in Volvo automobiles.

Dr. Andersson, Professor and Chairman, Department of Orthopedic Surgery at Rush University Medical Center, says that education is primary for the AS community “because of the rigidity of their spines.”

He says that everyone should be wearing their seatbelts “including patients with AS.” Dr. Andersson agrees with Dr. Myers that depending on an airbag for protection in an accident can be problematic: “While they provide additional protection, they do create a problem when the spine is kyphotic because of the forces created. Thus the seat belt clearly is the preferred protection in this respect.”

And as for the headrest, Dr. Andersson says that is the one feature that will afford you the most protection if your head is thrown backwards,

Everything in life is somewhere else, and you get there in a car.

~E.B. White, *One Man's Meat*, 1943

such as in the case of a rear-end collision. He suggests using head restraints as opposed to stock headrests, however. “Head restraints are actually better than headrests and can be retrofitted if necessary. Basically, the idea is to prevent the cervical spine from extending, which it cannot do in patients with AS very easily; for those reasons, the headrests may have to be flexed slightly forward to accommodate the typical forward flexion of an AS patient.

DRIVING WHEN YOU HAVE AS

So keeping all these vehicle-safety caveats in mind, should the fear of getting into an accident keep those with AS – with its inherent physical limitations – from slipping behind the wheel? Not at all. Since people with AS still need to get to where they have to go, driving can be a necessity – regardless of any physical limitations.

Granted, the unique problems faced by AS patients that could contribute to an increased risk in traffic include limited range-of-motion issues, such as stiffness in the neck or other parts of the spine and hips that can make it tough to maneuver a vehicle into a parking space or through an intersection where the driver needs to look around for oncoming traffic. There may also be peripheral joint involvement that doesn't allow free movement within the confines of a car.

But studies have concluded that people with even advanced AS can still drive safely by making simple modifications to their vehicle or to their driving techniques. Some intrepid AS patients have used their own ingenuity to come up with devices that help mobility-restricted drivers operate their motor vehicles.

NECESSITY IS THE MOTHER OF INVENTION

James Hall Jr. suffers from kyphosis of the spine – all vertebrae are fused except for C1 and C3. He says he has precious little movement in his neck and spine, but driving is a breeze for him due to his own ingenuity.

The 58-year-old San Diego support-group member who was diagnosed with AS in 1975 says that he uses a “device” that he saw mentioned in an arthritis magazine. He describes it as a “lazy-Susan” type piece of wood covered in foam padding and cloth that he parks himself upon when he drives.

“I use it for short-distance driving where it is perfectly tolerable,” he tells Spondylitis Plus. “It swivels my hips and allows me to sit more comfortably and gives me a bit of ‘extra turn’ when I come to an intersection.”

James says he also wears a cervical brace with added foam – backwards. He takes comfort in the fact that it provides him with a cushion at the base of his skull and top of his shoulders.

“I'm only looking for ways to be safer while hurtling through space in a steel box at 30 to 60 miles per hour,” he says with a chuckle.

MIRROR EXPANDS WORLDVIEW

And then there's Brad Sawyer, a Viet Nam-era vet with long-term AS. His spine, neck and ribcage have fused, leaving him unable to turn his neck and robbing him of nearly a foot in height. Out of dire necessity, he designed a 260-degree true-reflective mirror that allows him to clearly see all sides coming, completely eliminating the troublesome blind spots. “What you see in the mirror is actually coming, too,” he says, “it's a true reflection; nothing is smaller or larger in the vision.” “It was out of absolute necessity for me or I wouldn't be driving,” Brad, who lives Cape Cod, recalls. “I used to always have to have my passengers look around to see if other cars were coming; my wife worried about me driving alone. And one time I had a horrific near miss – and I can tell you that the sound of screeching brakes can be terrifying.”

The “MultiFlex Adjust-A-View Safety Mirror” (U.S. Patent No. 6926416) actually provides for a tool-free simple attachment to the driver's side sun visor giving the driver a distortion-free image reflection in both the left side's and the right side's blind spots, and you can easily see the passengers in the backseat, too.

Sawyer says he has approached various carmakers with his invention, but admits that they are proving to be a tough nut to crack. “But if it's helping someone drive who otherwise could not, that's all I care about,” he says with pride.

SOME TIPS FROM EXPERTS:

The following suggestions have been culled from many driving references sites and studies:

***Seatbelts:** Always use your seatbelts with a shoulder harness: The seatbelt is the single most important lifesaver in a crash. Studies by the Insurance Institute for Highway Safety (IIHS), industry group, recommends seat belts that are easier on fragile shoulders and ribs. Research by the Dept. of Transportation has shown that lap/shoulder belts, when used properly, reduce the risk of fatal injury to front-seat passenger car occupants by 45 percent and the risk of moderate to critical injury by 50 percent.

Brake lights: Extra high-mounted brake light to alert drivers behind you: Rae Tyson, a spokesperson for the National Highway Traffic Safety Administration (NHTSA) points to a 1986 NHTSA law change that mandated that all new passenger cars include a center high mounted stop lamp, or “CHMSL” – a third stop lamp, or brake light, mounted on the rear of a vehicle. “We saw a safety benefit— a decline in crashes,” he said. “Anything you can do to raise visibility of a vehicle is good.”

Special mirrors: Special mirrors that offer a wider view of what’s behind you could be fitted onto your car. These mirrors reduce the need to turn the head to check for cars in the driver’s “blind spot.” Many of these types of mirrors are on the market; however it is important to take time to practice parking using these new attachments.

Safe car: Own a car that is known to absorb the impact of a crash. See the additional research at the end of this story and research vehicles to fit your particular needs.

Headrests: The best seat and headrest are designed as one system; fixed head restraints reduce the risk of neck injuries by 25%; whereas adjustable head restraints only reduce the risk by 15%. Head restraint geometry explained: The necessary first attribute of an effective head restraint is good geometry. According to the IIHS, if a head restraint isn't behind and close to the back of an occupant’s head, it can't prevent a “whiplash” injury in a rear-end collision. Headrests are also advised to avoid sudden injuries to the neck as the stiff neck of an AS patient is more easily injured than a normal neck.

Cushions: A small cushion behind the back or under the buttocks can help maintain good posture when driving a car.

EACH SITUATION IS UNIQUE

The above suggestions are just the beginning. There is a wealth of rich material out there for drivers to consider for themselves; what works for one may not work for everyone. Each safety feature must be seriously considered for each individual circumstance.

And one more thing: Always do your best to avoid the jarring potholes when driving. Avoiding potholes is more than just a metaphor about life.

*See Bryan E. Bledsoe, DO, FACEP, “Ankylosing Spondylitis Patients Need Special Care,” Spondylitis Plus, July-August, 2006 issue and on www.spondylitis.org/; the article originally appeared in the Journal of Emergency Medical Services (JEMS); July 2006 • Volume 31 • Number 7, plus the article appears on SAA’s website: www.spondylitis.org/

“The mirror sells for \$19.99; to learn more about this safety mirror visit www.multiflexmirror.com

REFERENCES

SAA would like to thank The Ankylosing Spondylitis International Federation (ASIF) and The National Ankylosing Spondylitis Society of Great Britain (NASS), along with the late NASS director, Fergus Rogers, for his kind help with this story. We referred to their publication “Car Driving with Ankylosing Spondylitis” for assistance with research. The booklet was written by Dr. Jon Eriendsson, a rheumatologist based in Denmark.

British Society for Rheumatology;
1991, *Driving and Arthritis*
Jones, J.G. and Lassere, M.N.

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1986, *A Review of 100 Patients with Ankylosing Spondylitis*
Wordsworth, B.P and Mowat, A.G.

Journal of Emergency Medical Services (JEMS); July 2006
Volume 31 • Number 7

The Insurance Institute for Highway Safety – IIHS

The National Highway Traffic Safety Administration

ADDING INFORMATION FOR IMPORTANT FURTHER READING AND RESEARCH

Resources for user-friendly vehicles
where you can evaluate options for your particular needs:
http://www.arthritis.org/resources/travel/Car_Guide/Features_love.asp

Insurance Institute for Highway Safety
(for top safety picks in vehicles)
See: <http://www.iihs.org/ratings/>
And: http://www.iihs.org/research/bibliography/rear_crashes.html

The IIHS scores its frontal-crash results as Good, Acceptable, Marginal, or Poor. You can find ratings for all tested vehicles on the IIHS Web site, at: www.hwysafety.org.

Dynamically Tested Seat/Head Restraints
<http://www.consumerreports.org/cro/cars/safety-recalls/consumer-reports-suvs-pickup-rear-collision-and-whiplash-protection-106/index.htm>

10 Safety Checks
http://autos.yahoo.com/consumerreports/article/safety_checks.html

SAA's Annual Spring Online Auction

SAA's annual Spring online auction is just a few months away. The 7-day E-Bay event will spread awareness of AS and related diseases as well as raise funds for furthering SAA's mission to improve the lives of spondylitis patient throughout the country.

Auction items will include hotel packages to exotic locales, jewelry, artwork, and autographed collectibles from famous musicians, entertainers, sports stars, cartoonists, authors and more!

All proceeds from the auction will go to continuing SAA's important work in advancing spondylitis research, treatment and education. **Remember** – bid early and often!

Education & Support Meeting Facilitators

The people listed below are a vital part of our support system. They have volunteered to lead support groups across the US because they want to help. If you'd like to find out more about support groups and online meetings, pick up the phone or send an e-mail to:

Little Rock, AR	Mindy Hunter	(501) 351-6374	mindy.hunter@sbcglobal.net
Phoenix, AZ	John Kornfeind	(623) 910-4742	jmmkorn@cox.net
Long Beach, CA	Barbara Crofut	(562) 421-9698	crofutgr@verizon.net
Long Beach, CA	Frances Tomich	(562) 429-9685	not available
Orange County, CA	Kyle Brownfield	(949) 367-0430	kylebrownfield@msn.com
San Diego, CA	Mike Supancich	(760) 438-2962	supancichsr@sbcglobal.net
San Francisco, CA	Eric Passmore	(510) 644-0864	eric.passmore@gmail.com
Boise, ID	Tim Schaap	(208) 453-5006	tjschaap@msn.com
Boise, ID	Cindy Salo	(208) 850-3313	csalo11@hotmail.com
Fort Wayne, IN	Ken Prather	(260) 637-1705	pratherken@yahoo.com
Indianapolis, IN	Ken Prather	(260) 637-1705	pratherken@yahoo.com
Kansas City, MO	Linea Cooley	(913) 384-0728	linea_cooley@hotmail.com
Augusta, ME	Michelle Andrews	(207) 445-2885	qualey28@adelphia.net
Portland, ME	Penny McAuley	(207) 878-9414	spondylitis.portlandmaine@yahoo.com
Detroit, MI	Laura Russell	(586) 530-9988	mrussell.21@netzero.com
Holland, MI	Scott May	(616) 610-9130	smay@wmis.net
Portland, OR	Ken Henschel	(503) 579-8375	Ken.Henschel@comcast.net
Philadelphia, PA	Howard Tevelson	(215) 844-6075	hotbyht@yahoo.com
Myrtle Beach, SC	Alex Best	(843) 655-9762	alexbest@sc.rr.com
Dallas, TX	Elizabeth Smith	(972) 860-7179	elizabethsmith@dccd.edu
Houston, TX	Richard Powell	(409) 883-7822	rwpowell@gt.rr.com
Houston, TX	Stephen Haskew	(281) 337-3997	haskews@verizon.net
Washington, DC	Roger Stead	(703) 455-6005	rogerstead@aol.com
Seattle, WA	Paul Stevenson	(206) 524-2186	pastev@Safeco.com

- Teen Athletes with AS located in Orange County - contact WalkerRSM@aol.com for more info.
- Little Rock, AR, Boise, ID and Portland, ME now have Spondylitis Educational Support Groups!
- Support online from NY, NY with Michael T. Smith, spenser23@aol.com.

Online Poll

You can find this new Instant Poll on our website at www.spondylitis.org.

NEW POLL

Are you receiving Social Security Disability Insurance (SSDI) benefits?

- Yes
 No
 Yes, however, my co-pay is too high for me to afford the medication
 I currently am applying for SSDI.
 I receive other disability benefits.

OLD POLL RESULTS

Does your insurance cover TNF-blocker therapy for your spondylitis?

Yes, my co-pay is within my family's means.....56%
 Yes, however, my co-pay results in a hardship for my family15%
 No, my current medical insurance does not cover TNF-blocker therapy14%
 Yes, however, my co-pay is too high for me to afford the medication11%
 I receive assistance from a foundation, such as the Chronic Disease Fund to receive TNF-blocker therapy 4%
 Yes, even though my form of spondylitis does not have an FDA indication (off-label)0%
 No, since my form of spondylitis does not have an FDA indication (off-label) 0%

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Watch for our new website S.W.I.F.T. (Spondylitis Web Info for Teens), launching in early 2007! This website has information specifically for teens, ages 13-19, including stories from teens living with spondylitis, tips for school and sports and activities, and information from the doc about living with spondylitis as a teenager. Visit S.W.I.F.T. at <http://teen.spondylitis.org>

Reach Out and Touch Someone!

The SAA wants to help people with spondyloarthritis (AS or a related disease) connect with others in locations across the U.S. where a support group has not yet been established.

These people would like to connect with others in their area:

Robert Sauls, Modesto, CA

Kelly Riedesel, Weaverville, NC

Kerry Krow, Mountain View, MO

If you would like to "reach out" to any of these people, please contact Melissa Velez, Programs Coordinator, at melissa.velez@spondylitis.org

Are you interested in receiving more information about **ANKYLOSING SPONDYLITIS RESEARCH?**

Do you or a relative have Ankylosing Spondylitis?

If so, you can help a research effort to develop and validate a screening tool for potential AS patients.



If you are interested, please contact:

Study Coordinator
ASresearch@cshs.org
310-423-3032



Donate a Car today and help advance research tomorrow!

The process is quick and easy, includes free pick-up or towing, and best of all the proceeds go to a cause near and dear to your heart—The Spondylitis Association of America. The vehicle doesn't even have to run for you to donate it. Consult with your tax advisor prior to donating a vehicle. Call Helene Hart at 800-777-8189 X 229 for more information.

LOG IN

SAA members can now access exclusive content in the member area. Login with your email address and ZIP code at

www.spondylitis.org

research
Save the Date!



Spondylitis Association of America™

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Chicago
March 10, 2007

Los Angeles
May 5, 2007

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